painaustralia

Senate Community Affairs References Committee Inquiry into the Effectiveness of the Aged Care Quality Assessment and Accreditation Framework

November 2018

About Painaustralia

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain. Members include pain and other specialists, health practitioners, health groups, consumers and researchers. Painaustralia works with our network to inform practical and strategic solutions to address this complex and widespread issue.

Executive Summary

Painaustralia welcomes the opportunity to provide input to the Senate Community Affairs References Committee Inquiry into the effectiveness of the aged care quality assessment and accreditation framework.

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain. Members include pain and other specialists, health practitioners, health groups, consumers and researchers. Painaustralia works with our network to inform practical and strategic solutions to address this complex and widespread issue. The issue of safety and quality of care across aged care is an important one for us and our members. The consequences of untreated pain not only impacts the individual resident, but there is greater distress to their families and a greater care responsibility for staff.

With an ageing population, the Australian Bureau of Statistics projects that by 2064 there will be 9.6 million people aged 65 and over, and 1.9 million aged 85 and over, constituting 23% and 5% of Australia's projected population respectively , the issue of effective pain management in aged care is an issue in the interest of every Australian.

Chronic pain is a common condition among consumers of aged care services and effective pain management should be a core responsibility of all providers. Unfortunately, evidence suggests many residents with pain are poorly treated or under-treated.

In considering the Inquiry, Painaustralia makes the following recommendations:

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1. The Committee notes the prevalence of pain for residents of aged care and its relationship to incidents of mistreatment and severe behaviours.
2. Targeted national pain programs are developed and implemented in residential and community aged care for staff, consumers and family, friends or representatives.
3. Access to best practice pain management that adopts a multidisciplinary approach is further considered to inform policy development.
4. Embedding pain management across the new single quality standards as well as the new Aged Care Safety and Quality Commission to ensure providers have the capacity to manage chronic pain across aged care..
5. Prioritised implementation of public reporting of aged care performance data.
6. Improved access to information and support for advance care planning for people living with chronic pain and their families and carers.
7. Pain management is prioritised in aged care funding and policy reform and practice. The ACFI is refocussed on paying for quality and cost-effective outcomes based on measures of performance.
8. Consumer protections for residents to help them exercise their choice and rights in care.

Key Issues for Consideration:

Painaustralia has provided input to numerous aged care inquiries over the course of the last year. The main issues we propose raising in the context of this Inquiry are:

The prevalence of untreated pain in aged care

It is estimated up to 80% of aged care residents have chronic pain,[2,3] however more than half of residents (52%) in aged care facilities in Australia have a diagnosis of dementia while two in three (67%) require high-level care to manage behaviour.[4] This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and inability to report pain.

While chronic and acute pain is common among residents of aged care facilities, the evidence suggests that pain is misunderstood, poorly managed or undertreated, including the suboptimal use of analgesics.[5]

Evidence also shows that people with dementia in particular are living with pain and are being under-treated compared with cognitively intact persons, despite having similar levels of potentially painful disease.[6]

In one study, pain was detected in just 31.5% of cognitively impaired residents compared to 61% of cognitively intact residents, despite both groups being equally afflicted with potentially painful disease.[7]

The prevalence of acute and chronic pain among those with dementia should be recognised as a significant factor in severe behavioural and psychological symptoms of dementia (BPSD), which may be caused by the expression of emotion or unmet need that the person with dementia cannot otherwise express, e.g. pain, frustration, fear.[8]

People living with dementia have shared stories of an aged care system unable to meet their needs with reports of incidences that span physical, psychological and sexual abuse; inappropriate use of restraints; unreported assaults; and people in extreme pain at end-of-life not having access to palliative care.[9]

Untreated or poorly treated chronic pain can perpetuate the pain condition and severely reduce function and quality of life. It impacts personal relationships and can have profound emotional and psychological ramifications.

For many people, feelings of anxiety, sadness, grief and anger related to the pain can create a burden that is difficult to manage and may lead to the emergence of mental health problems. Major depression is the most common mental health condition associated with chronic pain, with rates of 30% to 40%, and there are also high rates of generalised anxiety disorder and post-traumatic stress disorder.[10]

These statistics are especially concerning in light of research by the National Ageing Research Institute that more than 50 percent of those living in aged care facilities have either anxiety or depression or both disorders, and just under 50 percent enter residential care with a pre-existing depressive condition.[11]

Cognitive or other communicative impairments of residents, inadequate training of aged care staff with day-to-day responsibilities for residents and workload that prevents adequate pain assessment are all barriers to effective treatment.[12] It can also lead to inappropriate use of physical or chemical restraints[13], misuse of pain medications and reliance on antidepressants.[14]

It is unsurprising that in 2016-17, the most common complaints made to the Aged Care Complaints Commission about residential care related to medication administration and management and falls prevention and post-fall management.[15]

Recommendation 1:

That the Committee notes the prevalence of pain for residents of aged care and its relationship to incidents of mistreatment and severe behaviours.

Quality of care

While ensuring access to appropriate staff levels is crucial to improve the quality of Australian aged care, the number of older Australians with chronic pain is significant, and the core business of both residential and home-based aged care services increasingly includes providing care to people living with chronic pain. It is critical that all aged care services have the capacity to provide quality care to people living with chronic pain, who are often frail and vulnerable, may have cognitive impairment and often have complex care needs.

- **Inadequate education and training of residential and community aged care staff leads to under-reporting of pain**

  Inadequate education and training of residential and community aged care staff is largely responsible for the under-reporting of pain in cognitively impaired residents—impacting some of the most vulnerable people in our society.

  A recent survey found that 41% of care professionals reported having received no training on assessment of pain in people with dementia, while 90% of care professionals indicated that additional training in dementia would be beneficial.[16]

  In its report Encouraging Best Practice in Residential Aged Care Program, the University of Wollongong states (p38):

  "One of the issues in residential aged care is that clinicians with the most knowledge and expertise (registered nurses and general practitioners) have the least involvement in the day-to-day care of residents."[17]

  The Australian Pain Society (APS) in its guidelines Pain in Residential Facilities – Management Strategies, indicates that staff workloads may also be to blame, with a lack of time for adequate pain assessment on a regular basis.

  Education and training of staff is vital for the provision of high quality residential aged care, because when people with dementia or other cognitive impairment are in pain, although they are unable to tell anyone verbally, pain may trigger behavioural changes and any such changes should be investigated. These changes may also be observed by carers or family members.

  It has been shown that Behavioural and Psychological Symptoms of Dementia (BPSD) are often an expression of emotion or unmet need (for example, pain)[18] and appropriate training would help to identify this.

  Aged care staff with day-to-day responsibilities for residents should have adequate knowledge and skills in pain assessment and management, including for people with dementia or other cognitive impairment.

  This would be consistent with the Australian Government's *National Safety and Quality Health Service Standards* (Standard 1 Governance and quality improvement systems), which highlights the need for governance systems that set out clear policies, procedures and protocols for "implementing training in the assigned safety and quality roles and responsibilities."[19]

  The Australian Pain Society (APS) has developed an evidence-based document specifically aimed at helping aged care facilities to meet best-practice pain management outcomes, Pain in Residential Aged Care Facilities- Management Strategies, 2nd Edition, which should be promoted across aged care as a useful resource that aids best practice pain management.

- **Insufficient education about best-practice pain management for aged care residents**

  Many older people believe that pain is a normal part of ageing and there is little potential for improvement. They also fear addiction to pain medications; they are concerned that pain may suggest worsening of disease; they are worried they will be seen as people who complain too much; and are also reluctant to seek help for fear of further functional dependence due to disease progression.[20]

  Programs such as Seniors ADAPT have shown that age is not a factor in being able to improve function and quality of life, given education in best-practice pain management and the right support.

  Residents who have sufficient physical and cognitive ability should have the opportunity to be actively involved in their own pain management. They should also be encouraged to develop a plan detailing their pain management wishes at end-of-life.

  Another important aspect that has a major impact on resident health and quality of care is nutrition. As identified in the Nutrition Chapter (2) in the Pain in Residential Aged Care Facilities: Management Strategies, 2nd edition, malnutrition and dehydration can directly affect pain experiences. Media reports and anecdotal consumer evidence suggests that there is insufficient attention paid to nutrition across aged care currently.

  Training for food service staff needs to be implemented and monitored, as often those putting together the menu are not qualified to ensure the menu meets the nutritional needs of the residents. Allowances for better quality food and more staff to assist with meal times could reduce malnutrition and improve the pain experiences and quality of life of residents in aged care facilities, this can be cost effective considering the current cost of malnutrition. Taking a multidisciplinary approach to embedding areas like nutrition across aged care are crucial in improving outcomes.

Recommendation 2:

Targeted national pain programs are developed and implemented in residential and community aged care for staff, consumers and family, friends or representatives.

Regulatory frameworks and implications for safety and quality of aged care

In reviewing the incidences of abuse in aged care such as Oakden Nursing Home in South Australia, what has become clear is that developing industry standards and protocols is critical to ensure providers establish systems for aged care staff to conduct regular pain assessments for individual residents.

Currently no such standards and protocols are in place, and without them, there is no requirement for providers to implement this essential level of care for individuals. Notwithstanding acute pain from recent injury or surgery, the vast majority of cases of pain experienced by aged care residents are chronic pain. Chronic pain is usually considered as pain that has lasted beyond the time expected for healing following surgery, trauma or other condition—usually three months—then it may be considered a chronic illness.[22]

Despite the high prevalence of pain in our aged care facilities and the high rate of unmanaged pain, the prevalent Australian Aged Care Quality Agency's Accreditation Standards mention pain only in brief and in vague terms:

Standard 8.2 Pain management: All care recipients are as free as possible from pain." [23]

There is no requirement for a best-practice approach to care and no requirement to help the resident achieve better quality of life. The standard also fails to acknowledge the need for ongoing pain assessments or the need to identify pain in non-verbal patients.

A significant body of research has shown that medication alone is not an effective solution and that a holistic approach to pain management, known as multidisciplinary pain management, is the best way to minimise the impact of pain, reduce disability and improve function and wellbeing. This is a key recommendation of the National Pain Strategy.[24]

Recommendation 3:

Access to best practice pain management that adopts a multidisciplinary approach is further considered to inform policy development.

The standard also fails to acknowledge the need for ongoing pain assessments for non-verbal residents. Cognitively intact residents may also face challenges in communicating pain, which could lead to under-reporting and under-treatment. If residents cannot express their pain and the workforce is not trained to manage BPSD then pain is not identified

The current accreditation process for aged care facilities relies on self-assessment, with facilities inspected by the Australian Aged Care Quality Agency just once a year and assessors speaking to only a minimum of 10% of residents during inspections. Over 95% of facilities pass accreditation which seems extraordinary in light of genuine quality of care issues such as poor pain management.

The risk of overlooking serious failures is therefore high, especially in the case of people with dementia or other cognitive impairment. In people with cognitive impairment who are non-verbal, untreated chronic pain can result in BPSD and lead to inappropriate use of chemical and physical restraints.[25]

It is estimated that about half of people in aged care and about 80% of those with dementia are receiving psychotropic medications, often for management of BPSD. There is sound evidence to suggest that in some cases these medications have been prescribed inappropriately[26]

Professor Brian Draper, Conjoint Professor, School of Psychiatry UNSW, in a submission to the Senate Inquiry into the Care and Support of People with BPSD said:

"I am firmly of the view that this long term overuse of psychotropic drugs in residential care is largely indicative of a combination of a number of factors – poor facility design, poorly trained staff, inadequate numbers of staff and lack of suitable activity programs for residents. The behaviours being treated by drugs are exacerbated or indeed at times caused by these issues. Psychotropic drugs are used because GPs and residential care staff can see no other solution.

- **Lack of consistent quality indicators**

Aged care in Australia is unique in that there are no nationally consistent and measured quality indicators. There is much to be learned in this regard from the public health system. Another example of how this might work is provided in the health care sector by the Australian Commission of Safety and Quality in Healthcare (ACSQHC), through the development and implementation of the National Safety and Quality Health Service (NSQHS) Standards.

Work is being done in this area through the development of single set of quality standards – the Aged Care Quality Standards, which will be implemented by 1 July 2019.[27]

However, it is important to note the Standards only establish the minimum acceptable level of service for accreditation, rather than providing any insight or guidance into whether a provider is delivering high quality care. While the single set of standards do take a more consumer directed approach, there are issues that need to be carefully considered to ensure that consumers aren't adversely impacted.

The aim to move to consumer directed care provisions can fix some systemic issues, however this approach too will not work in a regulatory sense. Market-based incentives do not work in a system that is operating at capacity or under supply. Many residents have no choice but to accept any facility available.

The roll out of a single set of quality indicators may assist in the comparison across residential aged care facilities resulting in greater transparency in relation to quality for consumers. There may also be a need to develop a more nuanced approach to Accreditation which would include whether a facility has met or exceeded the expected outcomes.

Painaustralia is also concerned that pain management is not being adequately addressed through the new standards. For instance, we are concerned to note that the new aged care quality standards do not acknowledge or consider the high risk and prevalence of chronic pain, despite nearly 80% of residents in residential aged care reporting chronic pain and despite the clear need for providers to have specialist capacity to manage pain appropriately.

We recognise that from the perspective of a service provider the concept of person-centeredness should mean the needs of each individual are understood and considered regardless of their unique situation. However, as the peak organisation representing and advocating for the needs of people with chronic pain, it is our role to ensure the needs of people with chronic pain are identified and supported. This is particularly significant around the discussion of what defines quality in aged care.

Recommendation 4:

Embedding pain management across the new single quality standards as well as the new Aged Care Safety and Quality Commission to ensure that providers have the capacity to manage chronic pain across aged care.

- **Lack of publicly reportable information**

  As highlighted in the many instances of consumer stories that have surfaced over the course of the past year, people often make the decision to move a loved one into a residential care facility purely on the basis of marketing and promotional information, predominantly provided by service providers. For a person or their carer considering placement in a residential aged care facility, or considering a new home care package provider, there is no consistent information that can aid in this decision-making process, for instance whether a facility or provider has met or exceeded the expected outcomes.

  Although the accreditation status of a residential aged care facility is publicly available, these documents are often difficult to interpret along with a lack of transparency as to how that relates to quality of care. Ultimately, it is vital that safety and quality mechanisms span consumer experience and quality of life within aged care services and that they are reported in a way that is both accessible and meaningful to consumers.

  The Ministerial Review of National Aged Care Quality and Regulatory Processes, led by Kate Carnell and Robert Patterson[28] made many recommendations including a star rated system for publicly available performance reporting across residential aged care facilities, as well as many other recommendations that can significantly improve on the current state of aged care quality and regulatory processes, and which should be implemented as a matter of priority.

Recommendation 5:

Prioritised implementation of public reporting of aged care performance data.

Barriers to accessing Palliative Care

In 2010–11, 75% of the 116,481 people aged at least 65 years who died in Australia had used aged care services in 12 months before their death.[29] The older a person was when they died, the more likely they were to have been accessing a service at the time of death.

There is evidence to suggest that many people, especially those with cognitive impairment, may experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation over their choices regarding end of life care.[30]

Nationally there were 231,500 permanent residents in Australia in 2014–15 with completed ACFI appraisals, yet only 1 in 25 of these indicated the need for palliative care.[31]

Managing pain at end-of-life is also an important consideration. It requires much more than analgesic and other medication to manage pain. It needs to prevent suffering but should also consider physical and psychological factors as well as spiritual and cultural beliefs and attitudes towards dying. For example, some people may not wish to receive a strong painkiller because of side-effects.

Clearly, right now our aged care services are not doing enough to provide recipients with access to appropriate and timely aged care. Ensuring the availability of high-quality palliative and end-of-life care services in aged care facilities and people's own homes, will enable more older Australians to have a good death, better support their families and carers during the dying and bereavement processes and facilitate the better allocation of scarce health resources, and this should be a pivotal consideration for this Inquiry.

Recommendation 6:

There should be improved access to information and support for advance care planning for people with chronic pain, their families and carers, as well as improved access to palliative care and pain management in aged care.

Impact of the Aged Care Funding Instrument (ACFI)

Residential aged care in Australia is predominantly funded by the Commonwealth Government through tax revenue with some finance coming from other levels of government and user co-contributions. Funding for each individual resident's care needs is determined by the ACFI with residents receiving a subsidy pay directly to the residential aged care provider.

The sum paid to the residential aged care provider is dependent upon the extent of the resident's care needs with the ACFI used to determine the total amount of the subsidy in three areas: Activities of Daily Living (ADL), Behavioural Supplements, and Complex Health Care supplements.

However, a recent evaluation of the tool notes it is 'no longer fit for purpose'.[32] Firstly, the ACFI subsidy level is not related to the factors that determine the need for care. This is a fundamental flaw in the ACFI as it inevitably leads to negative consequences where providers are rewarded for admitting higher subsidy residents who will be relatively less expensive to care for.

Professor Kathy Eagar, who led the research team, from the Australian Health Services Research Institute based at the University of Wollongong notes that the ACFI in fact provides 'perverse incentives' to providers [33], in effect rewarding them to keep elderly residents more dependent on care.

"A person who can't walk, is completely bedbound and who has a wound ulcer is very different to look after than a person who's mobile with a wound ulcer. And yet the ACFI treats those two items as though they're independent of each other."[34]

Most significantly, funding freezes to the ACFI in 2016, have resulted in the reduction of subsidy for the complex health care supplement which particularly impacts high-needs residents with complicated pain-management regimes. This has led to the removal of essential pain management services such as necessary physiotherapy and palliative care and diminished the capacity of the sector to provide appropriate levels of pain management in aged care.

Despite the recommendations of the University of Wollongong report,[35] the ACFI remains unchanged, compounding the issues faced by residents of aged care every day. It is vital the Inquiry consider the impact of the current aged care funding mechanisms on the safety and quality outcomes of care.

Recommendation 7:

Pain management is prioritised in aged care funding and policy reform and practice. The ACFI is refocussed on paying for quality and cost-effective outcomes based on measures of performance.

Empowered consumers and carers at the centre of aged care

Aged care in Australia remains one of the few services where consumers are not routinely engaged as part of the quality assessment process. On the contrary, current safety and quality systems have created outcomes where we see multiple reports of consumers indicating they are fearful of complaining or making negative comments about service quality because they fear retribution on their loved ones and have limited options to access alternative care.

Aged care in Australia needs to put consumers at the front and centre of service delivery, to match consumer expectations across nearly every other service sector in the country. We also need to empower consumers to have choice over the setting of their aged care services.

More and more consumers are now looking to age in place, with demand for home care packages and community based aged care far exceeding current supply. Building awareness of pain and its management is central to ensuring that consumers can be supported to self-manage their pain.

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then it is also important to recognise that carers are an essential part of the equation. Thirty six percent of all carers are over the age of 65 and most are caring for a partner,[36] however right now there is no emphasis on education and training programs that enable carers and informal support to provide essential community-based care such as holistic pain management.

Recommendation 8:

Consumer protections for residents to help them exercise their choice and their rights in care

Conclusion

While access to pain management is acknowledged globally as a fundamental human right and the Australian Government recommends best-practice care for aged care residents, Australia's aged care facilities are falling woefully short of effective pain care.

A significant number of residents have pain that is under-treated and are suffering unnecessarily (particularly those with dementia or other cognitive impairment), something that could be avoided through appropriate workforce education and training and adequate regulatory reform of the accreditation and funding system.

Leadership at a national level that prioritises a multidisciplinary, industry-wide approach will be essential to address these issues. It should include an Aged Care Quality Assessment and Accreditation Framework that supports quality of life. This will be achieved with best-practice pain management, along with appropriate education and training of staff (particularly in the identification of non-verbal signs of pain); appropriate funding that meets the needs of each aged care recipient; appropriate reporting policies and protocols; and education for aged and community care residents, their families and carers with sufficient capacity to self-manage their pain where appropriate.

We hope our submission provides the Committee with useful information to progress this significant Inquiry. Together with the Royal Commission into Aged Care Quality and Safety, we have a generational opportunity to create an aged care environment that affords dignity to the older and frail- some of the most vulnerable people in our society.

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